

The History of the Mental Health Consumer Movement

December 17, 2009





Contact Us

SAMHSA ADS Center

4350 East West Highway, Suite 1100
Bethesda, MD 20814

Toll-free: **1-800-540-0320**

Fax: **240-744-7004**

Web: <http://www.promoteacceptance.samhsa.gov>

E-mail: promoteacceptance@samhsa.hhs.gov

*The moderator for this call is **Ruth Montag**.*



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

<http://www.promoteacceptance.samhsa.gov/>



Disclaimer

The views expressed in this training event do not necessarily represent the views, policies, and positions of the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), or the U.S. Department of Health and Human Services.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

<http://www.promoteacceptance.samhsa.gov/>

Questions

At the end of the speaker presentations, you will be able to ask questions. You may submit your question by pressing “*1” on your telephone keypad. You will enter a queue and be allowed to ask your question in the order in which it is received. On hearing the conference operator announce your name, you may proceed with your question.





Speakers

Sally Zinman

Sally Zinman is a consultant primarily working as a consumer relations specialist with the Office of Consumer Relations, Alameda County (California) Behavioral Health Care Services. Active in the mental health consumer/survivor empowerment movement for over 30 years, she founded the Mental Patients' Rights Association in 1977 in West Palm Beach, FL, that developed an all-volunteer, client-run community center and shared living space. From 1997 to 2007, Zinman was the executive director of the California Network of Mental Health Clients, a statewide client advocacy organization that she and other clients founded 26 years ago. Zinman's commitment to the rights of people with mental health problems comes from her own horrendous experience in the mental health system. Working for the self-determination, freedom of choice, and empowerment of others who followed her, she has dedicated her life to ensure that what happened to her as a person labeled "mentally ill" would not happen to others. Sally co-edited and wrote articles for *Reaching Across: Mental Health Clients Helping Each Other* (1986) and *Reaching Across II: Maintaining Our Roots/The Challenge of Growth* (1994), used throughout the country as manuals for understanding and starting self-help programs.





Speakers

Su Budd

As one of the few remaining and active founders of the national mental health consumer/survivor movement, Susan Estelle (Su) Budd has a unique perspective that brings the founding principles of the early days to today's movement. She has expertise in movement history, organizational development, and peer/mutual support systems. Su has been a consultant to a variety of established mental health organizations and agencies including the National Institute of Mental Health, the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration, State Departments of Mental Health, local mental health centers, consumer run organizations, and the Kansas Governor's Mental Health Planning Council. She is a contributing editor of *Reaching Across: Mental Health Clients Helping Each Other*. Su is currently the director of the Leadership Academy sponsored by the Kansas Consumer Advisory Council for Adult Mental Health, the statewide consumer/survivor organization in Kansas.

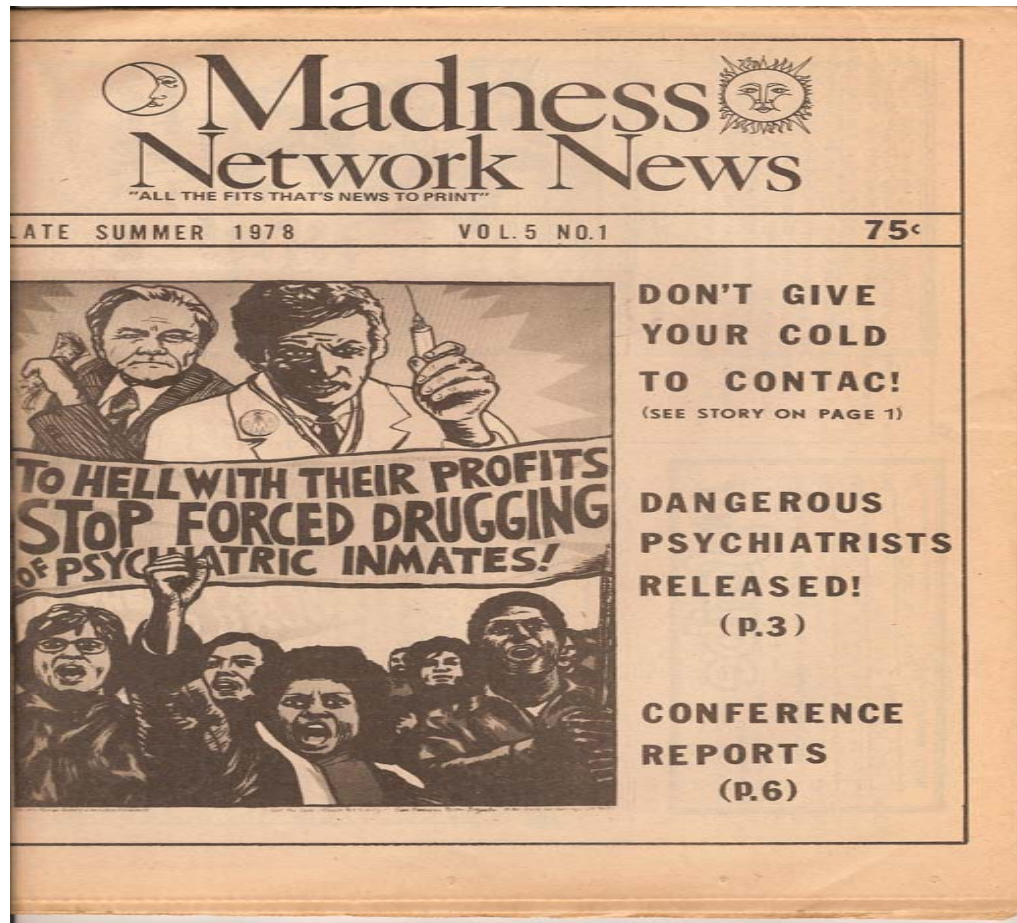


Speakers

Gayle Bluebird, RN

Gayle Bluebird, RN, has been active in the consumer/survivor movement since the early 1970s. She is a peer coordinator for the Office of Technical Assistance (OTA), part of the National Association of State Mental Health Program Directors, in Alexandria, VA. She conducts training at hospitals all over the country, promoting dialogue and communication between providers and service recipients and the development of comfort rooms. She has written and edited two manuals—*Participatory Dialogues* and *Reaching Across With the Arts*—with funds from Substance Abuse and Mental Health Services Administration (SAMHSA). In 2006 she produced and edited a film/video entitled “Leaving the Door Open: Alternatives to Seclusion and Restraint,” also for SAMHSA. Most recently she completed *Paving New Ground: Peer Roles in Inpatient Settings*, a guidebook on developing peer roles that is available through OTA.





History of the Consumer/Survivor Movement

Sally Zinman

Introduction

- In the 1960s and 1970s, social change movements were part of our culture. Inspired by the African-American civil rights movement and civil unrest and resistance, women, gays, and people with physical disabilities organized for social change.
- At this time, the big State hospitals across the country were being shut down, and new laws limiting involuntary commitment and its duration were being instituted. For decades, mental patients had been denied basic civil liberties, suffered systemic inhumane treatment, and spent lifetimes locked up in State hospitals.
- Anecdotally, once released from these mental hospitals, people began meeting together in groups outside the hospital. These former “patients” shared feelings of anger about their abusive treatment and the need for independent living in the community. Their peers validated their feelings. From these isolated groups across the country, a new civil rights movement was born. It was predicated on the desire for personal freedom and radical systemic change; it was a liberation movement.

The Beginnings—1970s

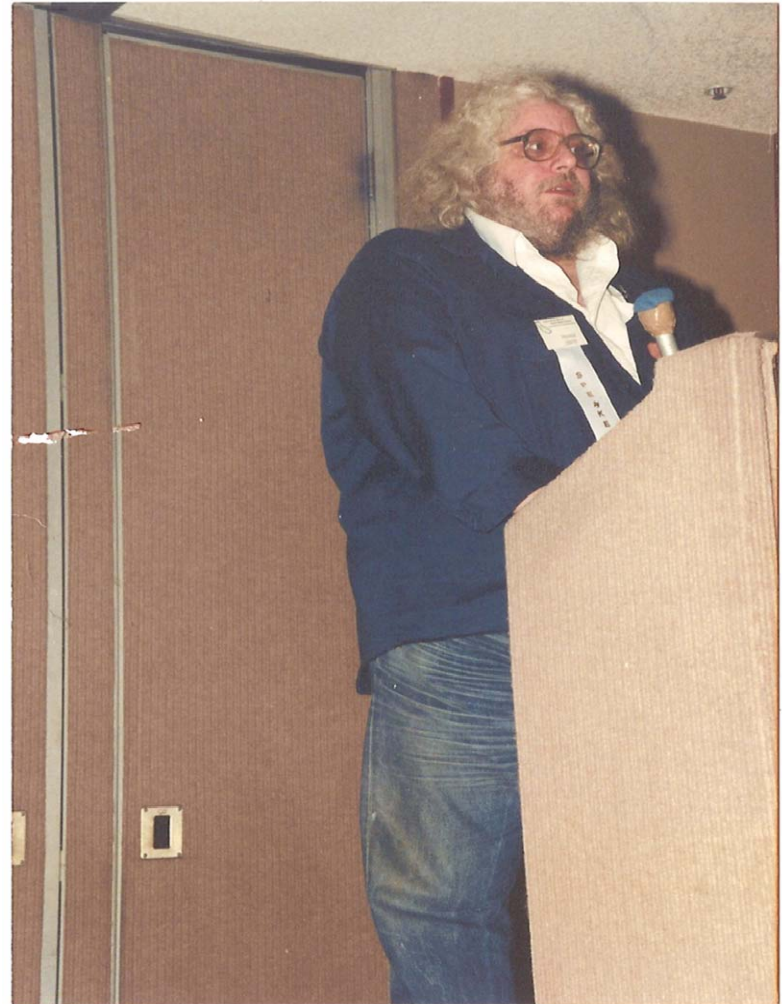
This decade was a time of finding each other and realizing that we were not alone, a time of militant groups and actions, a time of self and group education, and a time of defining our core values.

It was a time of finding and growing our voice out of the anger and hurt bred by the oppression of the mental health system. It was a time of separatism as a means of empowering ourselves.

Processes

- Autonomous groups;
belief in local control
- No money from mental
health system
- Separatist
- No major outreach

Howie the Harp



Activities

- Political, militant activism—demonstrations
- Development and defining of values and positions
- Annual Conference on Human Rights and Against Psychiatric Oppression held at campgrounds and college campuses, unfunded
- *Madness Network News*, news vehicle for communication
- Small groups—mostly on two coasts, militant names, e.g., Network Against Psychiatric Assault, Insane Liberation Front, and Mental Patient Liberation Front
- Most common self-description was “psychiatric inmate”
- Self and group information and education
- Support, consciousness raising groups
- Landmark book published in 1978: *On Our Own: Patient Controlled Alternatives to the Mental Health System* by Judi Chamberlin

Principles

All within the context of a liberation movement for people diagnosed with mental illness, the following examples were some of the principles these groups developed:

- Against forced treatment
- Against inhumane treatment—medications, lobotomy, seclusion and restraints, and ECT
- Sanism
- Anti-medical model, usually described as anti-psychiatry
- Emerging concept of consumer/survivor-run alternatives to mental health system
- Involvement in every aspect of mental health system

Transitions—1980s

The 1980s formed a transitional time:

- We made major movement decisions that left many of the more purist activists behind.
- We began the process of reentering the world that had so hurt us.

It was a time when new opportunities began, and, not coincidentally, some significant founding endeavors ended. There were indications that many of our goals were beginning to be realized: a transitioning from words to deeds, conceptualizing to implementing.

Processes

- Mainstreaming
- Centralizing
- Money from mental health system
- Collaborations/beginning reentry

Activities

- Growth of mental health system funded first self-help/peer-support programs, early drop-in centers:
 - 1983 On Our Own in Baltimore, MD
 - 1985 Berkeley Drop-In Center in Berkeley, CA
 - 1985 Ruby Rogers Drop-In Center in Cambridge, MA
 - 1986 Oakland Independence Support Center in Oakland, CA
- Federal Government's National Institute of Mental Health (NIMH) Community Support Program began to fund consumer/survivor-run programs:
 - 13 consumer/survivor-run demonstration projects funded in 1988
- Beginning of statewide consumer-run organizations—1983, California Network of Mental Health Clients
- Discontinuation of *Madness Network News* and decline of radical groups
- Discontinuation of Conference on Human Rights and Against Psychiatric Oppression
- Many mental health system-funded trainings and conferences; first national Alternatives Conference in 1985
- Rights protection gains/legislation
- Growth of rights protection organizations—Protection and Advocacy, Inc.
- Beginning to walk inside; social change from the inside as well as the outside
- More consumers/survivors sitting on decision-making bodies

Fruition of Changes— 1990s and 2000s

The 1990s marked the fruition of changes that we had sought in the mental health system. Although our basic values remained the same, we rephrased them. Consumer/survivor-run groups, employment, and educational opportunities began to flourish. Attitudes about chronicity began to change to recovery.

The 2000s have brought an increase of all of the gains of the 1990s. However, advocacy gains have created backlash, and service gains entail compromises: external and internal threats. The consumer/survivor movement itself is becoming more diverse and inclusive and developing a national voice.

Principles

The same principles as the earlier days are expressed in positive rather than negative ways:

- Self determination and choice
- Rights protections
- Stigma and discrimination reduction
- Holistic services
- Self-help/peer-support programs
- Involvement in every aspect of mental health system —
“Nothing About Us Without Us”
- Concept of recovery (encompassing all of the above)

Activities—1990s

- Employment in mental health system, as well as self-help programs, including consumers/survivors in mental health management level jobs—Offices of Consumer Affairs
- Big growth in self-help/peer-support programs with system funding
- Federal funding of two consumer/survivor-run technical assistance centers to provide technical support for consumers and self-help programs throughout country (in time grew to three centers)
- Multiple training and learning opportunities
- Noticeable consumer/survivor involvement at most levels of mental health system
- Consumer/survivor participation and partnership with other constituency mental health groups
- Beginning of client-run research, research on self-help/consumer-run programs, and consumer researchers
- Work with policy makers to legislate and otherwise influence policy
- Ongoing advocacy gains
- Described as “decade of recovery” (Bill Anthony, 1993)

Activities—2000s

- All of the activities of 1990s, amplified
- Incorporation of self-help/peer-support into system, e.g., Recovery/Wellness Centers, peer-support specialists, and medical-funded peer-support
- Development of mental health services that recognize the significance of trauma and spirituality
- More diverse and inclusive consumer/survivor movement
- Creation of National Coalition of Mental Health Consumer/Survivor Organizations, national advocacy voice for consumers/survivors
- Successful inclusion in the mental health system threatens the loss of our consumer/survivor values
- Some advocacy losses with push to increase involuntary treatments such as outpatient commitment and “leveraged” treatment

System Culture Change

Evidence of system culture change as a result of consumer/survivor involvement at all levels of mental health system:

- Consumer/survivor values embedded in Mental Health Services Act, ballot initiative passed into law by CA voters:
 - Voluntary promotion of self-help/peer-support programs
 - Involvement of consumers/survivors at all levels of mental health system
 - Involvement of consumers/survivors as part of and in training of mental health work force
 - Promotion of recovery as a goal
- SAMHSA's National Consensus Statement on Mental Health Recovery reflects basic consumer/survivor principles.
- Concept of Recovery inspired by and attributed to consumers/survivors:

“We envision a future when everyone with a mental illness will recover.” —*Achieving the Promise: Transforming Mental Health Care in America*, The President's New Freedom Commission on Mental Health, July 2003
- Consumers/survivors have initiated new genres of services: Consumer/survivor-run programs and peer-support are essential components of most mental health systems.



**Leadership Training in California by National Empowerment Center,
partially supported by SAMHSA**

**The scope of our achievements of
the past is an indicator of the
possibilities for our future.**

Our Past as a Beacon for the Future

A History of the Mental Health
Consumer/Survivor Movement

Su Budd

Origins of the Consumer/Survivor Movement—Early 1970's

- How were people with mental health problems viewed?
- Coercive treatment was a common occurrence
- Consumers and psychiatric survivors began to speak out

Relationship between Professionals and Consumers/Survivors—Early 1970s

- A radical caucus of American Psychological Association acknowledged abuses in the mental health system.
- A caucus member decided to meet with representatives of local consumer/survivor groups.
- Planning began for the first annual Conference on Human Rights and Psychiatric Oppression, held in 1972. This conference became an annual event.
- The Conference on Human Rights and Psychiatric Oppression went through several name changes as the movement grew in scope.
- How did consumers/survivors fund these conferences?
- Professionals who supported consumer/survivor efforts to organize reported that they experienced negative consequences.

Achievements and Happenings during the Early Movement

- Patient Bill of Rights passed in Kansas State legislature.
- Disenchantment with the old State hospital system was growing.
- Mental health services moved into the community.
- Professionals who were helpful to the movement still reported negative reactions.
- Consumers/survivors began to participate on mental health planning boards in local settings.
- Consumers/survivors began to publish articles in their own self-funded publications. Later, consumer/survivor literature appeared in professional journals.
- The concept of recovery in mental health was born. This idea started in the 70s and 80s as consumer/survivor personal accounts rejected the idea that consumers/survivors could not get better.

The Consumer/Survivor Movement— 1980s

- For the first time, NIMH sought consumer/survivor consultants to participate in a variety of efforts.
- A few professionals, primarily at the Federal level, recognized the courage and skill of members of this movement.
- The National Conference on Human Rights and Psychiatric Oppression demonstrated at the American Psychiatric Association Conventions.
- I spoke to professionals at the American Psychiatric Association.
- Consumer satisfaction surveys were implemented.

The Effect of the Alternatives Conference

- NIMH funded the first Alternatives Conference in 1985, and participants redefined their identity.
- Two national organizations of consumers/survivors grew out of networking after the Alternatives Conference.
- NIMH funded the production of two technical assistance manuals (written by consumers/survivors who wanted to organize for advocacy and/or peer-support).
- The focus of the early Alternatives Conferences changed.
- The first statewide consumer/survivor organizations were established.

The Consumer/Survivor Movement— 1990s

- With the help of government and other grants, several technical assistance centers were set up.
- Consumers/survivors began to seek jobs in the mental health system.
- Consumers as Providers training programs were established at some universities.
- Consumers/survivors advised mental health agencies on program development and policy making.
- Committees at the local, State, and Federal levels had consumer/survivor representation, including the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration.

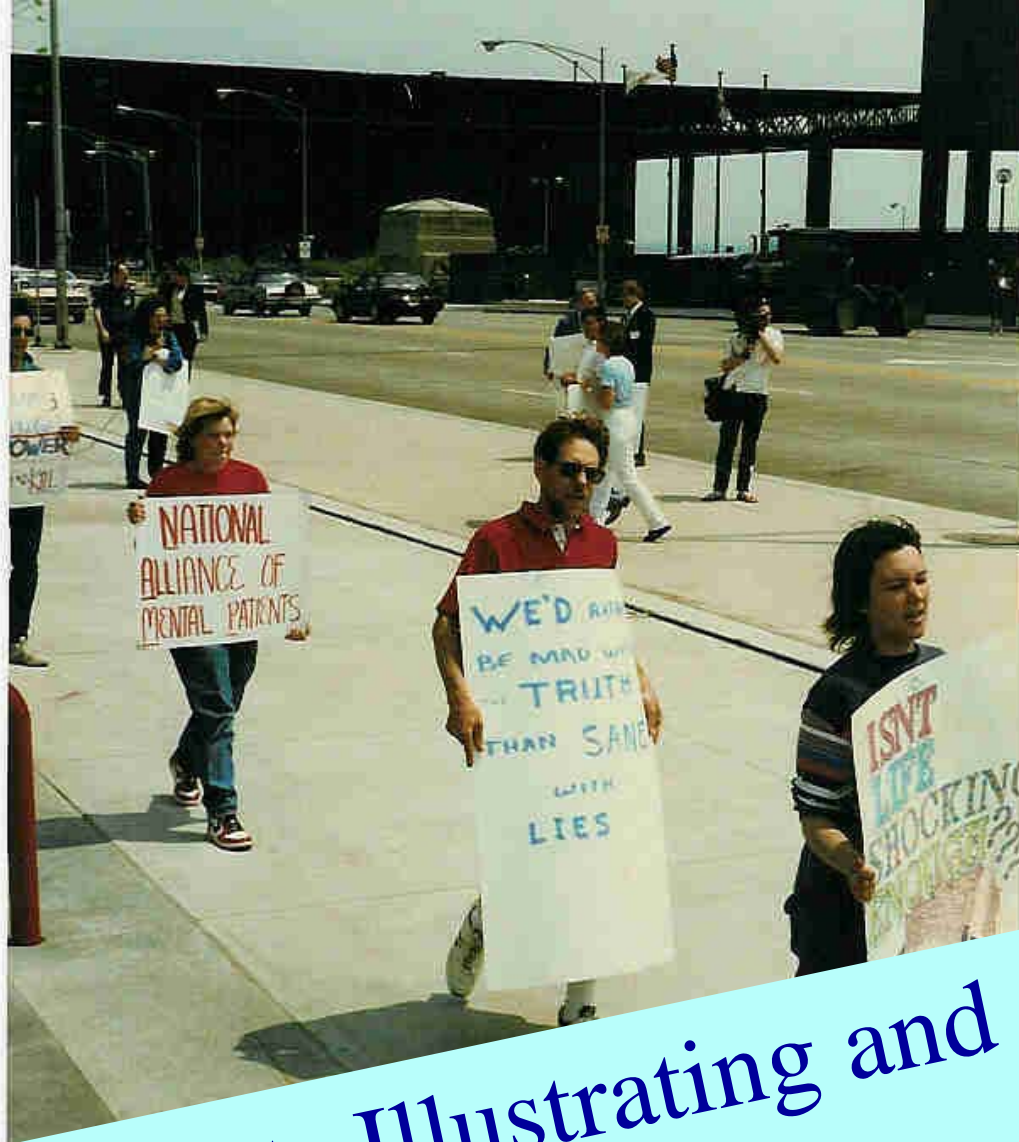
The Consumer/Survivor Movement Today—Achievements

- Prominent consumers/survivors are becoming known as recognized authorities in the field of mental health.
- Consumers/survivors are working alongside professionals and publishing protocols for achieving recovery.
- Peer-Support Specialist training and certification programs are more widespread and reimbursed by States and Medicaid.
- Peers work in community and inpatient settings as peer specialists.
- Professionals who support the movement are in the majority.
- Five national technical assistance centers exist.
- Funds are available to help consumers/survivors organize and attend national conferences.
- Today, most professionals are talking with their clients about hope and recovery.

The Consumer/Survivor Movement— Remaining Issues

- Involuntary treatment is still commonplace.
- Seclusion and restraint have not been eliminated.
- Too many people with mental health problems continue to end up in jails, in prisons, and on the streets.
- Funding issues adversely impact access to care.
- There is still stigma in the mental health system against consumers/survivors who work within the system.
- Consumers/survivors live nearly 25 years fewer than the rest of the population.
- Electroconvulsive Therapy (ECT) is still used, causing mild to severe memory loss.

*Many thanks go to the Kansas
Consumer Advisory Council for Adult
Mental Health for giving me the time to
write this presentation.*



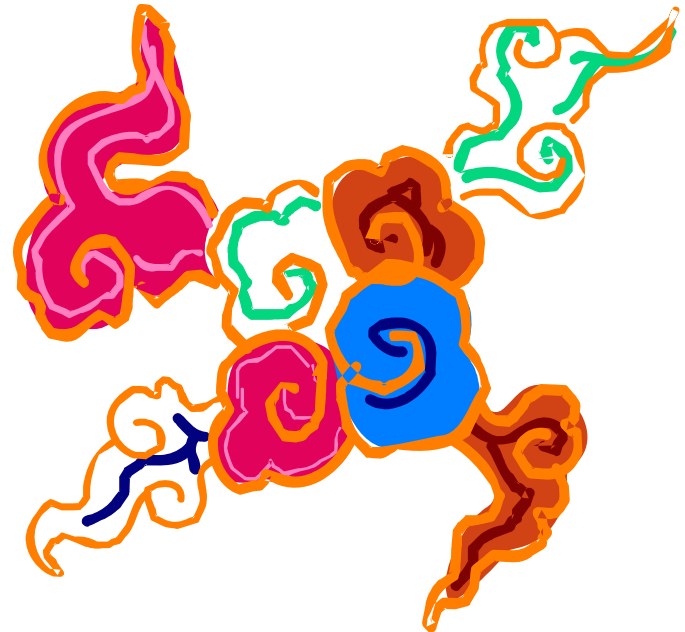
Arts Illustrating and Making History

Gayle Bluebird, RN

1970s

The Beginnings

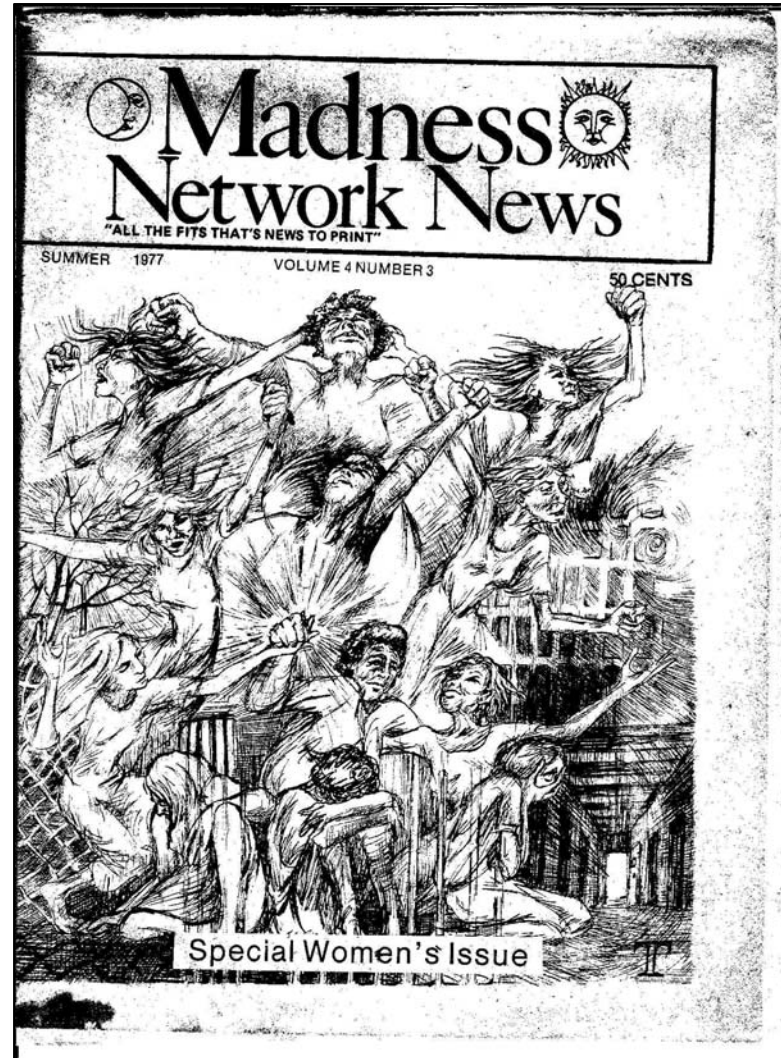
- Art was used to reflect anger, outrage, protest, and political ideology
 - Posters
 - Newsletters
 - Chants
 - Songs
 - Music
 - Poetry



Madness Network News

A national newsletter
published from the 1970s to
the 1980s

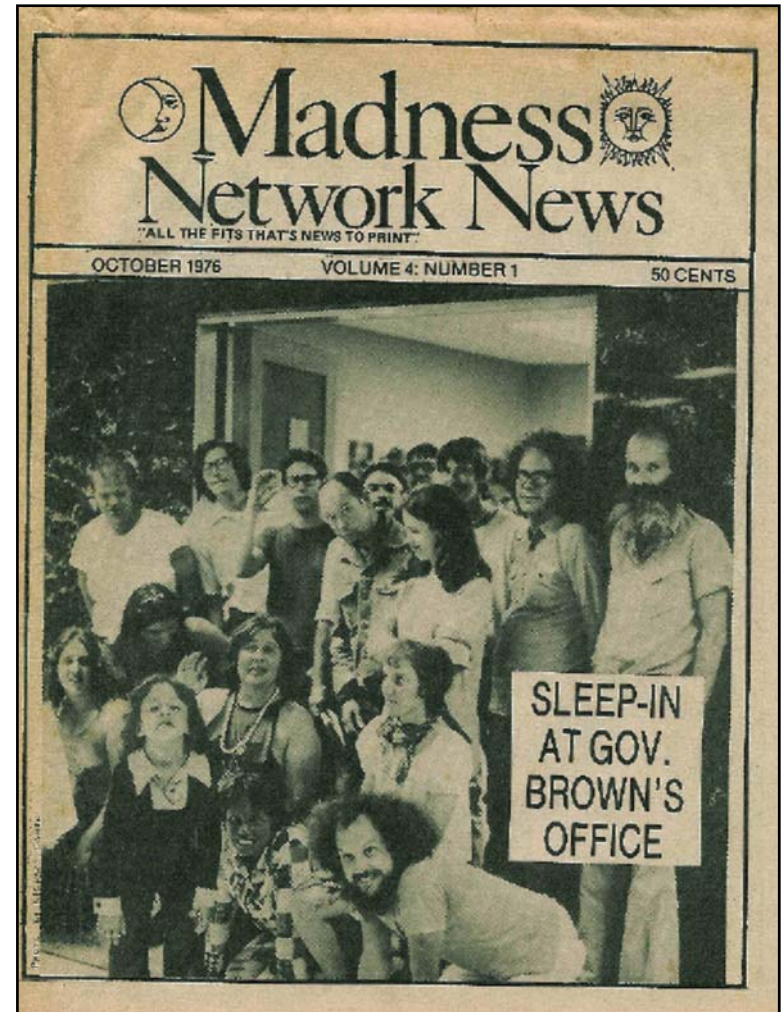
Cover by Tanya Tempkin
Berkeley, CA



Madness Network News

1976 Cover

Photograph of a 30-day “sleep-in” protest in then-Governor Jerry Brown’s office to protest deaths and abuses in State hospitals in CA



Howie the Harp

“Crazy folk (as he called us) are the most talented people in the galaxy. Instead of diagnosing, locking up, and treating us, the world should recognize our true worth and support our talents, creativity, and sensitivity,” said Howie the Harp, who carried a harmonica with him everywhere, to make music, mediate conflict, and create peace.



Cookie Gant



1949–2003

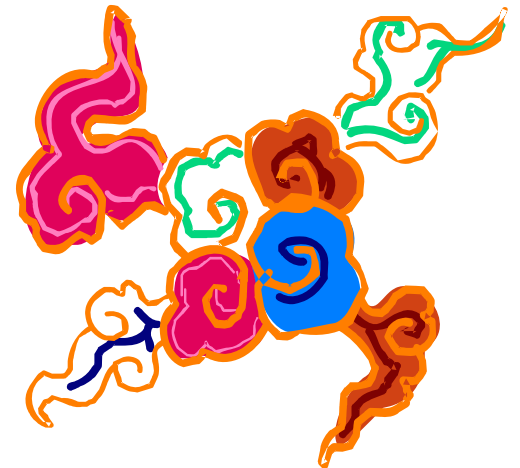
“Artiste Extraordinaire”

Early activist, outspoken poet, and performer, she spoke as a person with a disability, shock survivor, lesbian, and seller of buttons and other wares.

The 1980s

Transitioning with the Arts

- Talent Shows
- Drop-in Centers
- Formation of Arts Organizations
- Self-help Research Projects
- Individual Artists
- Media Projects



Talent Showcase

“Social Change” players who performed at various Alternatives Conferences

<http://www.alteredstatesofthearts.com>

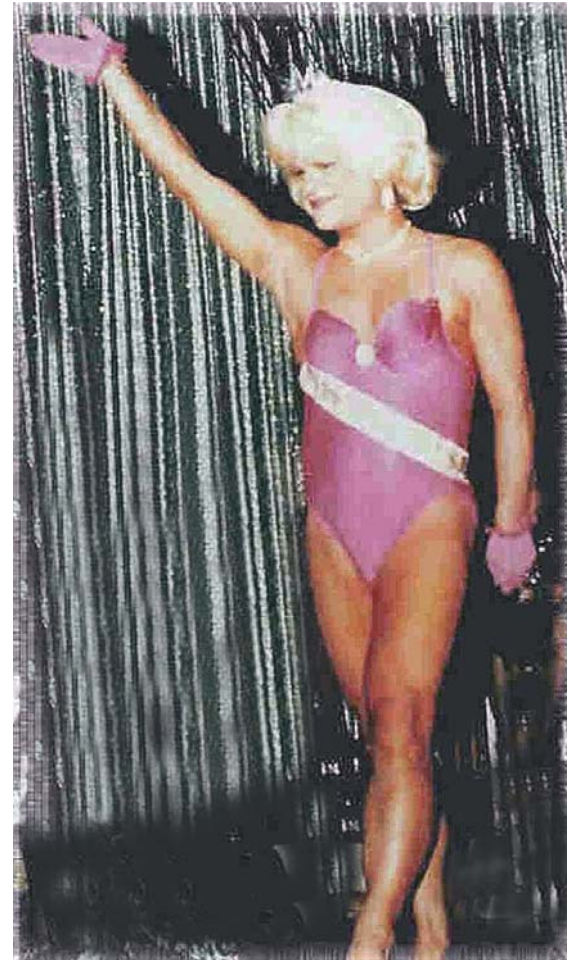


Mark Davis

Philadelphia, PA

“Drag with a Tag”

Mark created his act to educate and raise consciousness about being gay, living with HIV, and having mental health issues. He received a VOICE Award in Los Angeles, 2009.



Second Step Players

Uncasville, CT



Second Step Players (formed in 1985) is a theater troupe that writes and performs original comedy and drama about the experience of being labeled with a mental health problem. Seeking to promote recovery and community change through creativity and art, the troupe performs 20 shows per year and recently received two SAMHSA transformation grants for skills-building pilot programs.

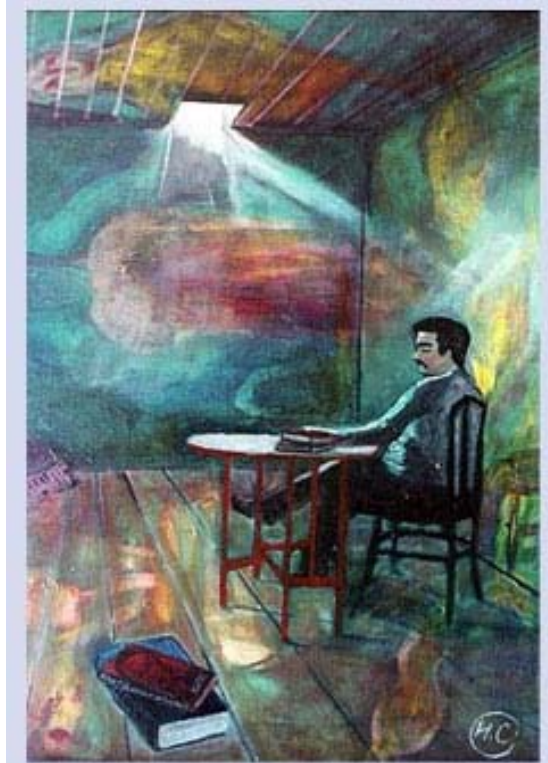
<http://www.artreachheals.org/>

Jean Campbell

CA, 1987

Well-Being Project

- Research by and for mental health clients
- 500 persons interviewed
- 61% of clients stated creativity was essential to their well-being
- 24% stated they lacked creativity in their lives



Alone and Waiting
1984 oil on canvas
24" x 18"

art by Jean Campbell

Sybil Noble

Kansas City, MO



“Fearful of Diagnosis”



“Fractured”

Sybil is the only (known) mental health consumer/survivor to receive an Eli Lilly scholarship to attend art school. Her work has been exhibited in many local and national exhibits. With her husband, she co-directs a drop-in center in Kansas City with an emphasis on the arts.

The 1990s to Today

- Arts depicting recovery
- Holistic healing
- Guidebook on the arts
- Self-determination and self-sufficiency
- Addressing childhood trauma
- Confronting stigma and discrimination
- Arts and peer-support



Sharon Wise

Washington, DC



“Wanting Love”



“Zyprexa Walk”

“Things I can’t say in words I can say through my art; I paint in vibrant colors that reflect my culture and history of trauma and childhood abuse.” Sharon will be known not only as a talented visual artist but for her amazing “Butterfly” dance performance that brings audiences to tears. She received a national VOICE Award in 2008.

Wambui Bahati

New York City

Once a Broadway performer, Wambui later created a one-woman show, *Balancing Act*, based on her mental health experiences. She has also written an enlightening memoir, *You Don't Know Crazy*, that describes how she found inspiration and exhilaration out of despair.

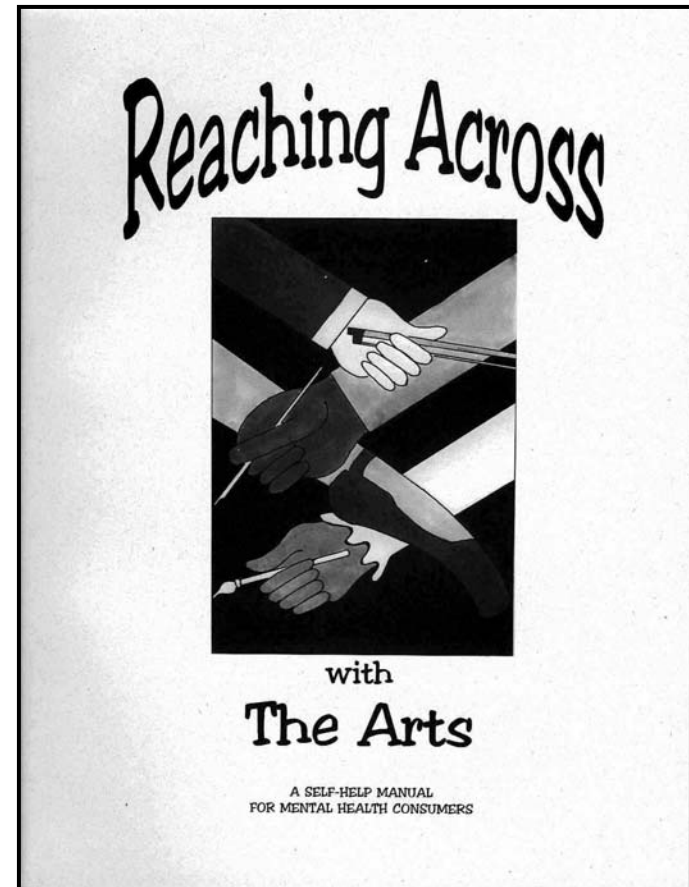
<http://www.wambui-bahati.com>



Reaching Across with The Arts

A self-help arts guide published in 2000 with funds from CMHS, containing information that is still relevant and helpful to mental health consumers/survivors today.

<http://www.alteredstatesofthearts.com>

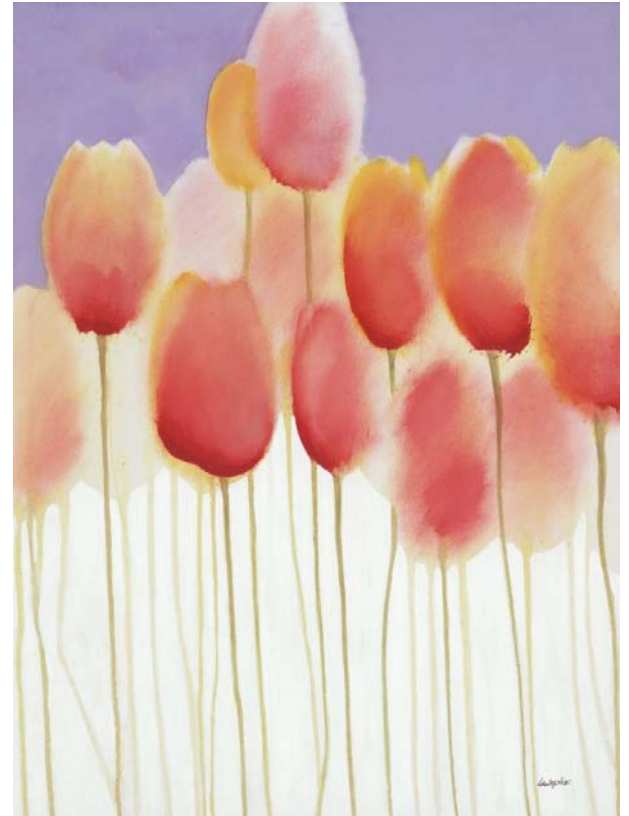


Jerome Lawrence

Atlanta, GA

Jerome is a talented and nationally recognized artist known for his works of beauty and color. One of his paintings in the *Tulips are People* series hangs in the rotunda of the Carter Center in Atlanta, GA.

<http://www.jeromelawrence.net>



Tulips are People IX

Michael Skinner

Manchester, NH

Michael writes songs on issues related to his childhood abuse and on spirituality, hope, love, and recovery. He has written, recorded, and published three CDs of his music; he also speaks on the prevention of childhood sexual, mental, and physical abuse. Art is his primary source of income.

<http://www.michaelskinner.net>
<http://www.michaelskinnermusic.com>



Meghan Caughey

Portland, OR



“Hugging Form”

From Meghan’s early work

Meghan’s transformative art evokes strong emotions when viewing it, from the very deep and painful to the light and joyful. “My life has been rather raw and hard to look at, but I have tried to make it into something that has beauty...and art has done that for me.”

<http://www.meghancaughey.com>

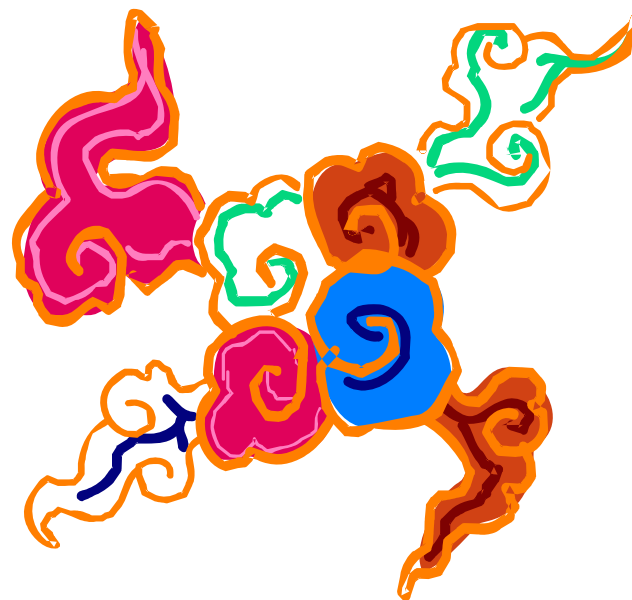


“Lotus with Sparks”

From Meghan’s lotus series later in recovery

Special Projects and Partnerships

- Traveling exhibits
- Media projects
- Memorials



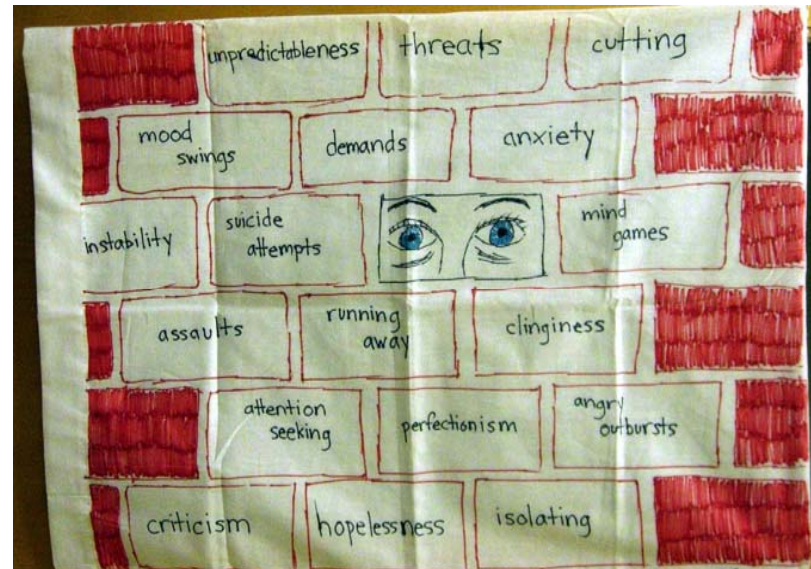
Pillows of Unrest

Fulton State Hospital Exhibit

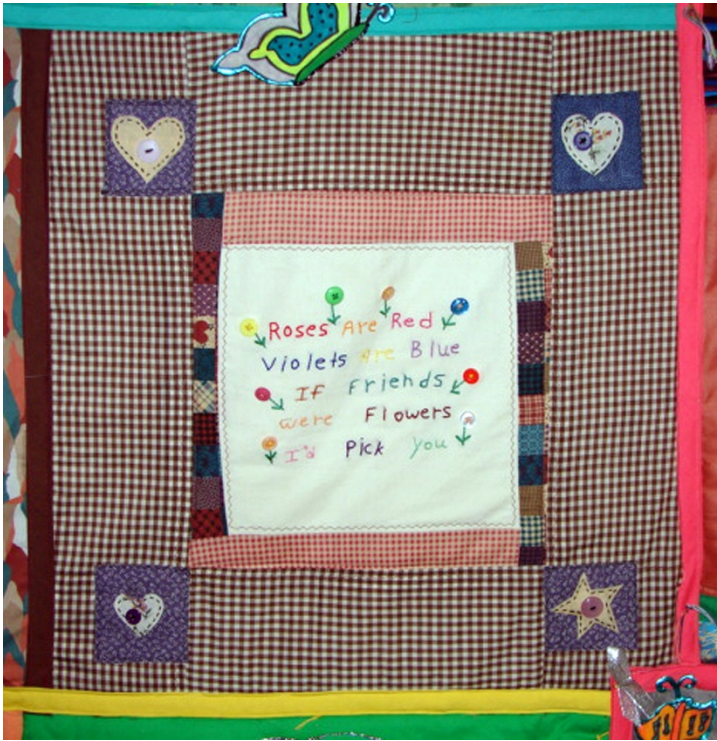
Fulton, MO

- “If pillows could talk, they would tell a story of our struggles”
- Reflects issues of recovery and effects of stigma
- Showcases a traveling exhibit of poetry and art on pillowcases
- Illustrates a clothesline exhibit you can do!

<http://www.alteredstatesofthearts.com>



S.I.D.E.S. Quilting Project



S.I.D.E.S, a wellness center in St. Louis, MO, started a fabric quilt project with the theme of recovery to demonstrate to the community that we are capable, caring, and loveable people. The chosen theme was “Wings of Change”—thus, the butterflies scattered throughout the quilt.

Gilberto Romero

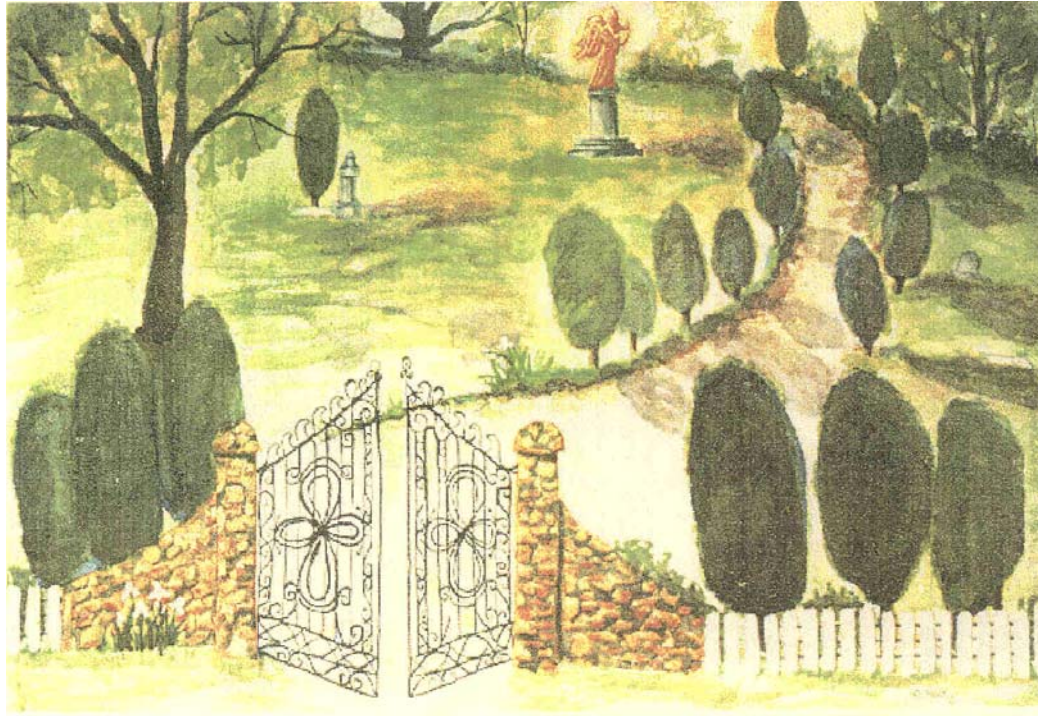
Cuarteles, NM

Gilberto is a longtime consumer/survivor/activist, photographer, and national leader who continues to do a weekly radio show, “Informas de Esperanza.”



The Cemetery Project

Milledgeville, GA



Cemetery restored with beauty to honor 25,000 people who had been buried in unmarked graves at Central State Hospital since 1842. Awareness of this project, coordinated by Larry Fricks and Pat Deegan, has spread across the U.S., and many others like it now exist at other hospital cemeteries, including the cemetery at St. Elizabeth's Hospital in Washington, DC.

Our Future

- Art as a significant player in mental health transformation
 - Arts and trauma
 - Arts and wellness
 - Peer specialists trained to use the arts
 - Artists going on the road, showcasing their work and stories



Resources

- Altered States of the Arts. Web site: <http://www.alteredstatesofthearts.com>
- ARTREACH—Second Step Players Theater Group. Web site: <http://www.artreachheals.org>
- Bahati, Wambui. Web site: <http://www.wambui-bahati.com>
- Campbell, J. The Well-Being Project.
- Caughey, Meghan. Web site: <http://www.meghancaughey.com>
- Cemetery Projects (Pat Deegan & Larry Fricks). Web site: <http://www.patdeegan.com/links.html>
- Informas de Esperanza (Information of Hope) Radio Program. Contact: Gilberto Romero, 505-989-7441
- Lawrence, Jerome. Web site: <http://www.jeromelawrence.net>
- Noble, Sybil. E-Mail: arkfriends@kc.rr.com
- S.I.D.E.S.
- Skinner, Michael. Web sites: <http://www.mskinnermusic.com> and <http://www.michaelskinner.net>
- Wise, Sharon. E-mail: thehouseofsharon@msn.com

Presentation by
Gayle Bluebird “Henrietta”
Bluebird Consultants





More Information

For more information, contact

Sally Zinman

510-639-1335

510-644-1916 (home office)

szinman@acbhcs.org

Su Budd

913-205-7554

[subudd@freeshell.org](mailto:subbudd@freeshell.org)

Gayle Bluebird

352-525-3195 (home office)

352-219-1095 (cell)

gaylebluebird@aol.com



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

<http://www.promoteacceptance.samhsa.gov/>



Survey

We value your suggestions. Within 24 hours of this teleconference, you will receive an email request to participate in a short, anonymous online survey about today's training material. Survey results will be used to determine what resources and topic areas need to be addressed by future training events. The survey will take approximately 5 minutes to complete.

Survey participation requests will be sent to all registered event participants who provided email addresses at the time of their registration. Each request message will contain a Web link to our survey tool. Please call **1-800-540-0320** if you have any difficulties filling out the survey online. Thank you for your feedback and cooperation.

Written comments may be sent to the Substance Abuse and Mental Health Services Administration (SAMHSA) ADS Center via e-mail at promoteacceptance@samhsa.hhs.gov.

